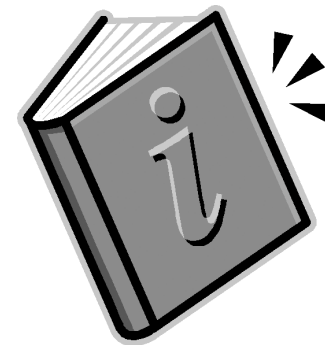


Welcome to the Kidney and Urinary Program



Providing Client Centred Care

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Chaplainsext. 33263
7 days a week: 24 hours a day

Pharmacists (Inpatient)ext. 33366
Monday to Friday: 8:00 a.m. to 4:00 p.m.

Pharmacy (Outpatient - Hospital)..905-521-6170
Pharmacy (CAHS)905-573-4850

Physiotherapistsext. 33246

Primary Care Nurses (PCN)ext. 36049
Monday to Friday: 9:00 a.m. to 4:30 p.m.

Social Workersext. 33101
Monday to Friday: 8:30 a.m. to 4:30 p.m.
Answering machine on off hours.

Transplant Coordinatorsext. 33236
Monday to Friday: 8:00 a.m. to 4:00 p.m. Answering
machine when out of office.

Community Resources:

The Kidney Foundation of Canada
Hamilton District Chapters.....905-318-8627

Websites:

Baxter Information Service:
www.kidneydirections.com

Kidney Foundation of Canada: www.kidney.ca

St. Joseph's Healthcare Hamilton: www.stjoes.ca



Telephone Numbers

St. Joseph's Hospital905-522-4941
Direct Dial905-522-1155

Hospital Units and Centres

Hemodialysis Centre (Hospital)ext. 33601
Hemodialysis Centre (CAHS)ext. 34854
Monday to Saturday: 7:30 am to 11:30 p.m.
After hours: On Call Nurse is available by asking
switchboard to page: 11:30 p.m. to 7:30 am each
night and on Sundays.

Nephrology Unitext. 33224
7 days a week: 24 hours a day

Peritoneal Dialysis Unit Clinicext. 33638
Monday to Friday: 7:00 a.m. to 5:00 p.m.

Renal Transplant Unitext. 34048
7 days a week: 24 hours a day

Health Care Team:

Dietitian ext. 33604
Monday to Friday: 9:00 a.m. to 5:00 p.m.

Nephrologists' Office905-521-6049
A Nephrologist and Nephrology Resident are
available 24 hours a day, 7 days a week.

Occupational Therapistext. 33306

About this book

This book will help you learn about the Kidney and Urinary Program at St. Joseph's Healthcare in Hamilton, Ontario. We are a regional treatment centre for people with kidney disease.



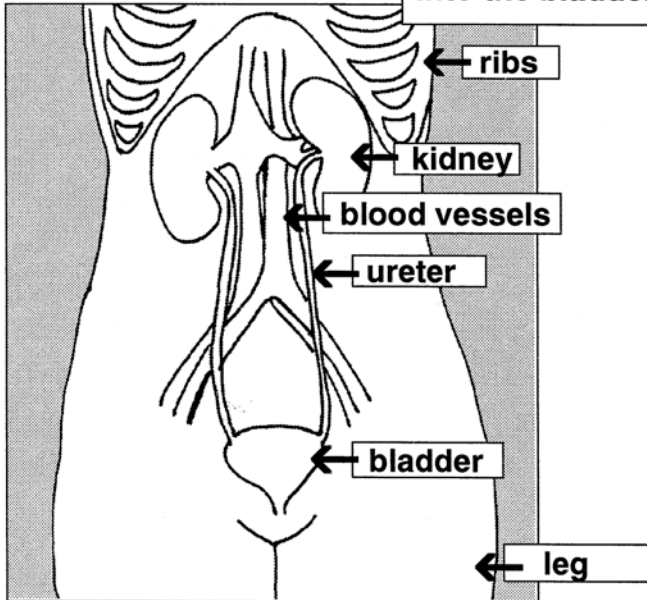
You are in the Kidney and Urinary Program because you have kidney problems. Most people have a lot of questions about the treatment and the care they need.

We hope this book will answer some of your questions.

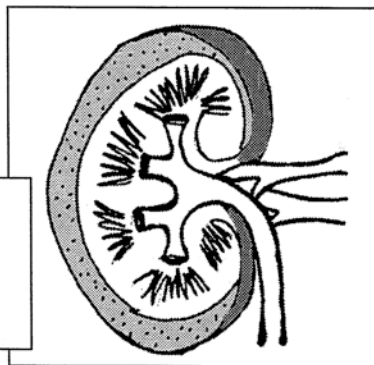
What is happening to me?

Your kidneys are not properly filtering the wastes, extra salt and water from your blood. The wastes, extra salt and water build up in your body. When this happens, you may begin to feel weak, tired, and nauseated. Your hands and feet may swell and your eyes may be puffy. You may feel irritated. You may not think as clearly as before. Your skin may look paler. These are all changes caused by kidney disease.

As the blood flows through the kidneys the nephrons take out the waste, salt and extra water. Urine is made and flows down the ureters into the bladder.



This is what a kidney looks like inside. There are many nephrons inside each kidney.



Your Health Care – Be Involved

Your safety is our concern. In order to have the best health care here are some ways to **Be Involved**:

- Ask questions and talk about your concerns
- Know the medications you take and why you take them
- Carry a current list of medications and herbal products you take to share with all health care providers
- Carry a list of your current medical conditions, allergies, past problems and surgeries
- Make sure you know what to do when you leave the hospital, clinic, program or doctor's office

When you are involved, you can make better decisions about your treatment plan. For more information there is a booklet called "Your Health Care – Be Involved" published by the Ontario Hospital Association. Ask a member of your health care team for a copy. You can download this book in many languages from www.oha.com

If you are a patient in the hospital you can watch the program "Your Health Care – Be Involved" on your bedside television. Turn on Channel 82 – the free patient education channel to learn more.

Advantages	Disadvantages
You can travel.	You need to come to the Transplant Clinic regularly.
	You may need more than one kidney transplant in your lifetime.

Kidney Function Program (KFP)

The Kidney Function Program offers education, support and care for people who have kidney disease and have not started dialysis.

The goals of this program are:

- to delay or prevent the progression of kidney disease
- to promote health and prevent complications through education
- to manage related health issues
- to prepare for end-stage renal disease

Nephrologists refer people to the Kidney Function Program. If you are in this Program the Nephrologist, Primary Care Nurse or the Clinic Nurse will see you at each visit. You may also see other members of the Health Care Team when needed. These include:

- Diabetes Nurse
- Renal Dietitian
- Social Worker
- Vascular Access Coordinator
- Physiotherapist

Members of the Health Care Team

You will meet many people on your Health Care Team. The Team works closely with you, your family and friends. You may have questions or concerns about your care. Members of the Health Care Team will help with any problems you have.



Your Nephrologist is a doctor who is a kidney expert. Your Nephrologist will work with you to decide on your treatment. The Nephrologist will direct any care you have in the hospital and when you are home. You may see other special doctors such as a Urologist, a Vascular Surgeon, and Residents depending on your treatment plan.

Your Primary Care Nurse or PCN works with you and your Nephrologist. You will see your PCN in the clinic, in the dialysis unit and in the hospital. Your PCN knows your medical history and works with the Health Care Team to plan your care.

Special Care Nurses such as Hemodialysis Nurses, Peritoneal Dialysis Nurses, Renal Transplant Nurses and Nephrology Unit Nurses will help you depending on your special needs. These are Registered Nurses who will help you learn about your kidney problem, help with your dialysis treatments, and teach you how to manage your treatment and general lifestyle.

Advantages	Disadvantages
You can eat your meals while doing your dialysis.	There is a cost for setting up the room and paying for utilities. Some expenses are tax deductible.
No travelling especially in bad weather.	You need a clean area for the machine and lots of room for the supplies.
You take greater responsibility for your own health.	You need to be able to put 2 needles in your arm for each treatment.

Kidney Transplant

Advantages	Disadvantages
This treatment is the most similar to your own kidneys.	Waiting for a donor kidney.
You may be free of dialysis after.	There are risks when having surgery.
You can follow a normal diet and may not have fluid restrictions.	There is a risk of rejecting the new kidney.
You can follow a normal schedule and may have more energy.	You need to take medication for the rest of your life. There are side effects from these medications.

Advantages	Disadvantages
You are able to travel after some planning.	2 needles are put in your access for each treatment.
	Waste build-up between treatments may give you symptoms.
	You need to take medication each day.
	Your diet is more restricted in potassium and fluids than with Peritoneal Dialysis treatments.

Home Hemodialysis

Advantages	Disadvantages
You are in the comfort of your own home.	You need a supportive partner.
<p>You have the flexibility of using the machine when it is convenient.</p> <p>You are able to work around other things going on in your life.</p> <p>You have a more normal life as you create your own schedule.</p>	It is a big responsibility especially when problems come up.

You will get to know the Nurses well as they co-ordinate your care with members of the Health Care Team. Your nurses will also be your advocates and supports when you want help talking to members of the team.

A Dietitian will help you and your family learn about your special diet. Your diet is a very important part of your treatment. It will help prevent the build-up of waste products in your blood. It will also help prevent the build-up of fluid in your body.



On your first visit, the Dietitian will ask about your eating habits at home. This is called a diet history. Together, you will work out a diet plan that fits your lifestyle. The plan will be based on whether you are getting dialysis treatments or not at this point in time. The Dietitian can offer cooking tips, recipes and meal planning. This will help you adjust to your new diet.

Following a diet is an important part of your treatment plan. The better you understand and follow your meal plan, the better you will feel. The Dietitian can follow your progress from your blood tests and weights and let you know how well you are doing. When you have questions about your diet, your Dietitian can help.

The Social Worker can help you and your family cope with the changes of kidney disease. Kidney disease causes many changes in your life. For example, it may affect your ability to work, your living arrangements or your financial situation. You may not be able to work or may need to change jobs. Your Social Worker can help you and your family manage these changes.



There may be changes in the way you feel about yourself or others. You may feel anxious, distressed, sad, angry, or depressed. You may feel frightened or confused. It can help to talk about your feelings. Your Social Worker will listen and offer helpful advice. He or she can arrange family meetings if you wish. Together, you can talk about issues that are important to you and your family.

The Pharmacist will explain your medications and how they work. The Pharmacist can provide written information about your medication. You can also get devices to help you remember to take your medication.



Advantages	Disadvantages
You have support from the Unit and Clinic Nurses and the Kidney Foundation of Canada. You have help from the company that the equipment comes from using a 1-800 telephone number.	You will need to take medications each day.
You can stay at home and do your own dialysis.	

Hemodialysis in the Hospital or CAHS

Advantages	Disadvantages
The Hemodialysis Nurses always help you with your treatment.	You need to travel to a Hemodialysis Centre 3 times a week and plan your activities around this.
Most people have 3 treatments a week lasting 4 hours each time. You have free days between without dialysis treatments.	You need a machine to do this treatment.
No equipment or supplies needed at home.	You need surgery to make a dialysis access such as a fistula or graft. Some people do not like the way the access looks on the arm. The access may clot or become infected.

Advantages and Disadvantages of Treatments

Peritoneal Dialysis

Advantages	Disadvantages
<p>You have independence and control as you can follow a flexible schedule.</p> <p>You are in charge of your own dialysis and must take an active part in your treatment.</p>	<p>You need to do 4 to 5 exchanges each day and make it part of your life.</p>
<p>There are diet changes but these are less restrictive than a hemodialysis diet.</p>	<p>You have a permanent tube coming out of your abdomen.</p>
<p>Your check-ups are about once a month.</p>	<p>The tube makes you at higher risk for infection.</p>
<p>You have better control of your volume</p>	<p>Need a lot of space to store supplies at home.</p>
<p>There are no needles.</p>	<p>Your body image may change.</p>
<p>You are able to travel after some planning.</p>	<p>You cannot have tub baths or go swimming without permission from your Nephrologist.</p>

You may get your medications from the hospital pharmacy or from your own drug store. If you have a drug plan, bring your drug plan number or Drug Benefit cards with you to the pharmacy. Medication coverage changes after a transplant. Speak to your Social Worker about having a plan to cover the medication expenses, as these can be quite high.

There is a pharmacy at St. Joseph's Hospital and the Centre for Ambulatory Health Services. Please do not wait to run out of your medications before you get a refill. Getting a refill takes 48 hours.



The Occupational Therapist or OT will help you to be more independent at home. Your OT will look at the activities you do every day, such as dressing, bathing, and looking after your home. Together, you will look for ways to make your tasks easier and save energy. Your OT knows other people who may be able to help you. Your OT can help you obtain and learn about equipment that may be useful to you at home or at work. This may include a wheelchair, aids, and bathroom aids.

The Physiotherapist or PT will help you become more independent getting around. He or she will see how well you are able to get up, move about, walk and use stairs. You may be given exercises for certain muscle groups. The Physiotherapist may also advise you to use a cane or walker.

Many people with kidney disease have limited energy. The Physiotherapist will teach you ways to balance activity with rest so that you can go about your day. The hospital Physiotherapist may also talk to Physiotherapists in the community and give you ideas and resources that may help you manage at home.

Often the PT and OT work together to get equipment and resources you need.

Spiritual Care

A Chaplain can provide spiritual, emotional and religious support for you and members of your family. You do not need to follow any faith to use this service. The Chaplain can help you adjust to the changes in your life in order to live well in this new time. If you agree, the Chaplain can help you contact other support people for you such as your own clergy or leader from your faith tradition.



You may ask to see a Chaplain or you can call the Spiritual Care Department yourself at ext. 33263.

Call or drop in to the Kidney Foundation of Canada,
Hamilton and District Chapters:
35 Goderich Road, Unit 9
Hamilton, Ontario, L8P 4P2
Call: 905-318-4830

The Greater Ontario Branch is:
35 Goderich Road, Unit 9
Hamilton, Ontario, L8P 4P2
Call: 905-318-8627 or 1-800-414-3484

Peer Support Program

The Peer Support Program offers one to one help to those whose lives have been affected by renal disease. These trained volunteers, through their own experience, have an understanding of what you are going through. For further information call 905-574-5222



The Kidney Foundation of Canada

The Kidney Foundation of Canada is a national voluntary health organization dedicated to improving the health and quality of life of people with kidney disease.



The Foundation:

- funds research and related clinical education
- actively promotes awareness of organ donation
- advocates for high quality health care
- provides services for the special needs of people living with kidney disease

Services include:

- information and referrals
- patient manuals and brochures
- patient assistance programs - financial
- patient educational days
- peer support and self help groups
- bursaries
- dialysis camps for adults and children
- travel loans
- own and loan equipment programs

Community Care Access Centre or CCAC

The Case Manager of the Community Care Access Centre will arrange for any help if you need it at home. Your visiting Nurse will help you become independent in caring for yourself. This may include help with your medications, diet changes, treatments, and symptom care. The Visiting Nurse will help you return to your normal roles and routines. He or she will answer any questions you have at home. Other services CCAC can provide include physiotherapy, social work counselling, homemaking and others.



There are certain criteria that need to be met to qualify for CCAC Services. You can discuss this with your hospital Nurse, PCN or Peritoneal Nurse.

A Teaching Centre

St. Joseph's Healthcare is a teaching organization. This means you may have a student involved in your care under the direction of the health care team. We welcome students in all health care programs.

A Research Centre

St. Joseph's Healthcare is a research organization. Many new treatments and changes in health care have come from research done here.



You may be asked to take part in a research study. Be sure you understand the details of the study and how you would be involved before you sign a consent form for research. If you do not want to be in a research study, your care will not be affected.

Service Excellence

All of the staff, doctors, volunteers and learners at St. Joseph's Healthcare follow a set of "Standards of Behaviour". Our goals are to:

- treat everyone with dignity and respect
- work together to provide great care and service

Types of Treatment for Kidney Disease

Some kidney problems can be treated with medications and diet changes. While this works well for some people, others lose all of their kidney function.

When less than 10% of your kidneys are working, you will need dialysis treatments. You will need dialysis treatments for the rest of your life, unless you have a kidney transplant.

Dialysis treatments help to do the job your kidneys normally do. They help to filter wastes, extra salt and water from your blood. This prevents them from building up in your body. Build-ups to toxic levels can make your body go into shock.

Helpful Information

When you are sick and cannot do your own dialysis



Let your Nurses know if you feel sick. They will contact your Nephrologist. Together, you will decide on a dialysis plan.

When you are admitted to the hospital

If you are admitted to the hospital for medical reasons, the hospital Nurses will do your dialysis. Most people are admitted to the Nephrology Unit. You will dialyze in the hospital until you are well and able to do your own dialysis.

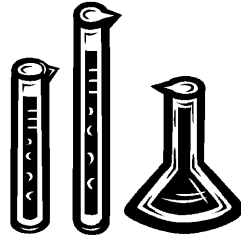
Medical Alert Identification



You need to wear medical alert identification all the time.

This will help you get the proper help in an emergency. You can get an application from the Social Work Department or the Pharmacy. Feel free to ask a member of the health care team to help you complete a form. You need to identify that you are a kidney patient and have an access or that you have had a kidney transplant.

A living related transplant happens when a sibling, parent or child donates a kidney. An emotionally related person such as a spouse can also be called a living related donor.



A living donor must have special blood tests done to look at the genetic match between the donor and the recipient. Other tests need to be done before a transplant can happen.

This process can take up to 12 months to complete. This is all organized through the Transplant Coordinator.



If you are on the transplant waiting list, your kidney would come from someone who has died and the family decides to donate the kidneys. This is called a deceased donor. It may take 10 years to find the best-matched kidney for you.

You will need to have many tests done before you can have a kidney transplant. The Transplant Coordinator will contact you about these tests after you meet with the Transplant Nephrologist. The Transplant Coordinator is available to answer any questions about the transplant process along the way.

Dialysis treatments prevent this from happening. Your Nephrologist and PCN will let you know when you need to begin dialysis. This depends on many things:

- how well your kidneys are working as checked by tests
- your body's water balance
- how well you are feeling

Types of Dialysis Treatments

There are 2 types of dialysis:

- peritoneal dialysis
- hemodialysis

Your Nephrologist will talk with you about the type of dialysis you need. This will depend on many things:

- the cause of your kidney problems
- any other medical problems you have
- your lifestyle
- your living arrangements
- your work situation

There are advantages and disadvantages for each treatment. These are charted starting on page 22. You can refer to this chart when you talk to members of the Health Care Team. It is important to ask questions and talk about your concerns as you are part of the team.

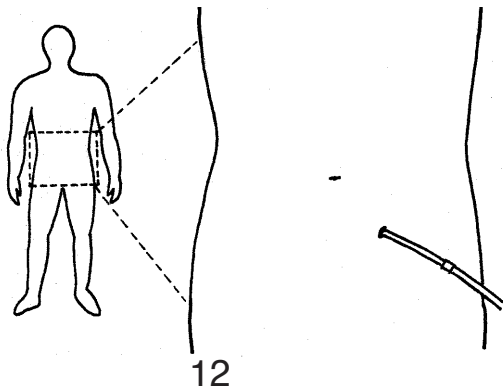
Peritoneal Dialysis as a Treatment

If you have peritoneal dialysis treatments, you will meet the team of Peritoneal Dialysis Nurses. The Teaching Nurses will help you learn what you need to know about peritoneal dialysis and how to do it yourself or with a care helper. When you go home, the Clinic Nurses will follow your care. They will help you with any questions or problems you have.

The peritoneal membrane is a lining on the inside of your abdomen. Peritoneal dialysis uses your peritoneal membrane as a filter. Wastes, extra salt and water are filtered from your blood through the membrane.

In order to use the membrane, the doctor makes a small incision below your belly button and off to the side. This is done under local anaesthetic.

A catheter is put in. The catheter is a hollow, flexible tube. It is about the size of a pencil. The catheter stays in the cavity surrounded by the peritoneal membrane all the time. The catheter is anchored in your body by a cuff. The part of the catheter outside of your body is taped to your skin.



It takes about 3 months to learn to dialyze yourself. The time it takes to learn is different for each person. To dialyze at home, you must always have a partner to help you. Your partner will need to learn about your dialysis too. It helps to start learning together before you begin dialysis. This can be arranged with the Unit and your Nephrologist.

Kidney Transplantation

Kidney transplant is another form of treatment for kidney disease. St. Joseph's Hospital does 50 to 70 kidney transplants a year.

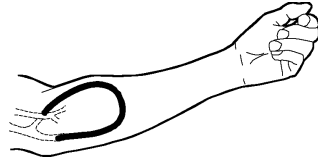
If you are thinking about a transplant, speak with your Nephrologist. Your Nephrologist will set up a meeting for you with the Transplant Nephrologist. This is a kidney doctor who specializes in transplants.

The Transplant Nephrologist will meet with you. Together, you will go over what having a transplant involves. Many factors are important in deciding whether a transplant is a good idea. Your age, the cause of your kidney problems, and your general health are some of these factors.

There are living kidney donors and deceased kidney donors.

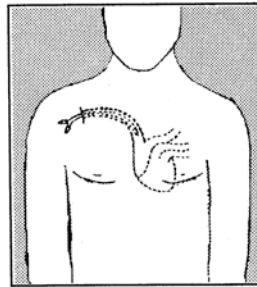
Graft

A graft is made by joining an artery and vein with a piece of soft tubing. This is done under the skin in your arm or thigh. You have a local anaesthetic for this surgery. It may take up to 4 weeks for your graft to be ready to use.



Central Venous Catheter

A central venous catheter is used if you need hemodialysis, when you do not have a fistula or graft. It can be used in emergencies and if another access is not working. It can be used right away for dialysis.



A central venous catheter is made of a special plastic material. The catheter is put into a large vein in your neck under local anaesthetic. The part of the tube outside your body is taped to your skin when you are not using it for dialysis.

Home Hemodialysis

You can learn to do hemodialysis at home. The Home Hemodialysis Nurses and Technologists will help you learn how.

A special dialysis solution flows through the catheter into your abdomen. The peritoneal membrane then works as a filter. The solution draws the wastes, extra salt and water from your blood. After a set time, this is drained back through the catheter into a bag. The bag of wastes is thrown away after each treatment.

There are 2 ways to do peritoneal dialysis:

- Continuous Ambulatory Peritoneal Dialysis called C.A.P.D.
- Continuous Cycling Peritoneal Dialysis called C.C.P.D.

C.A.P.D.

C.A.P.D. is usually done 4 times a day, every day. This means there is always dialysis solution in your peritoneal cavity. Each time you do a treatment it is called an exchange. You will be taught how to do C.A.P.D. at the hospital so you can do it at home.

It takes about 1 week to learn to do C.A.P.D. on your own. The learning time is different for each person. With C.A.P.D., you can work or go to school. You can travel. Many people on C.A.P.D. vacation in Canada, Europe and the United States.

The times you choose to do the 4 exchanges are more flexible. This allows you to fit them around your schedule. You will also need to adjust your diet when you are doing C.A.P.D. Your Dietitian will help you.

C.C.P.D.

Some people use a machine called a cyclor at home to dialyze at night. While you are sleeping, the cyclor is programmed to clean your blood. The Peritoneal Dialysis Nurses will teach you how to do this on your own.

Home Helper Program

People who are on peritoneal dialysis but cannot do the treatment by themselves go on the Home Helper Program. In this program, a trained Nurse comes to your home at night to start your dialysis. The Nurse then comes back the next morning to take you off dialysis. The Health Care Team decides who goes on the Home Helper Program.

Some areas offer a Home Helper Program and some do not. This depends on where you live.

Hemodialysis as a treatment

If you need hemodialysis treatments, you will go to the Hemodialysis Centre at St. Joseph's Hospital or the Centre for Ambulatory Health Services. There you will meet a team of Nurses and Technologists.

Since hemo means blood, hemodialysis is a treatment that filters wastes, extra salt and water from your blood.

An artificial kidney machine is used. This machine helps do the job your kidneys normally do. The artificial kidney is sometimes called a dialyzer. Each treatment takes about 4 hours. The time needed varies with each person. You may need to have treatments many times a week.

There are 3 types of accesses:

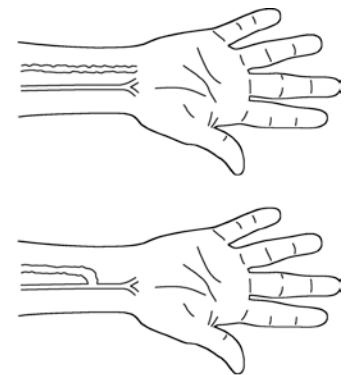
- fistula
- graft
- central venous catheter.

You, your Nephrologist and Vascular Surgeon will decide what access is best for you.

Types of Accesses

Fistula

A fistula is made by joining an artery and a vein in your arm. This surgery is done under local or general anaesthetic. The Urologist or Vascular Surgeon arranges this surgery.



You will need to exercise your fistula for 1 to 3 months after the operation. This will make it strong for dialysis. You can then use it for hemodialysis treatments.